

The Caregiver

Newsletter of the Duke Family Support Program

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Alzheimer's Disease Research Center

Duke Family Support Program

Program Director	Lisa Gwyther, MSW
Social Worker	Edna Ballard, MSW
Program Coordinator	Mary Trabert, MBA



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Subscriptions to this newsletter are available free to North Carolina residents. Call 800-672-4213.
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Duke Family Support Program
Box 3600 Duke University Medical Center
Durham, NC 27710
800-672-4213 (NC only) 919-660-7510
www.dukefamilysupport.org

Alzheimer's Association Contact Information

Eastern North Carolina Chapter

400 Oberlin Road, Suite 220
Raleigh, NC 27605
919-832-3732
800-228-8738
awatkins@alznc.org
www.alznc.org

Caregiver Education Conferences

African-American Conference, Apr. 21
Durham/NC Mutual Life Ins. building
New Bern, May 11
Craven Community College
Sanford, May 30
Lee Co. Life Enrichment Center
Fayetteville, June 7
Kiwanis Recreation Center at Honeycutt Park
Raleigh, June 19
Millbrook United Methodist Church
Goldsboro, Aug. 21
First Pentecostal Holiness Church
Henderson, Oct. 11
Vance-Granville Community College
Greenville, Oct. 23
St. James United Methodist Church
Lumberton, Nov. 14
Southeastern Agricultural Center

National Alzheimer's Association
225 North Michigan Avenue, Suite 1700
Chicago, IL 60601-7633
312-335-8700 800-272-3900
www.alz.org

Help Us Spread the Word

If you know of others who would find this newsletter useful, please tell them to call toll-free for a subscription. The Caregiver, published twice a year, is free to NC residents and \$10 per year for those out of state. Call **1-800-672-4213**.

Western Carolina Chapter

Main Office, Piedmont Region
3800 Shamrock Drive
Charlotte, NC 28215-3220
704-532-7392 800-888-6671 (24-Hour Helpline)
www.alz-nc.org
info@alz-nc.org

Mountain Regional Office

31 College Place, Suite D320
Asheville, NC 28801-2644
828-254-7363 800-522-2451

Foothills Area Office

260 1st Avenue NW, #218
Hickory, NC 28601-4757
828-267-7100

Triad Area Office

1315 Ashleybrook Lane
Winston-Salem, NC 27103
336-725-3085

Caregiver Education Conferences

Spirituality Workshop, May 1
Marion Senior Center

Activity Based Alzheimer Care: Building a Therapeutic Program CE for Activity Professionals
June 12 *Burlington*; June 16 *Hendersonville*

Alzheimer's Disease in the African American Community in Collaboration with the Duke African American Community Outreach Program (AACOP), October 27
Friendship Missionary Baptist Church Charlotte

23rd Annual Caregiver Conference, Nov. 1
Lake Junaluska (Haywood County)

Nine spring Memory Walks
www.alz-nc.org/MemoryWalk/index.htm

News and Notes

Prevalence of Alzheimer's Rises 10% in 5 Years

More than five million Americans have Alzheimer's disease, a 10 percent increase from the last official tally five years ago. The updated estimates are based on the rising occurrence of the disease with age. One in eight people 65 and over have Alzheimer's disease, as do 42 percent of those past 85. However, Alzheimer's disease affects younger people as well. Between 200,000 and 500,000 people younger than 65 have some early onset form of dementia. The recently released report by the Alzheimer's Association itemizes the cost to the federal government in Medicare spending. Care for a patient with dementia costs three times as much as care for the average beneficiary -- \$13,207 a year vs. \$4,454.

Study to Enhance Coping with Alzheimer's Family Caregiver Stress

Chronic or long-term stress can harm the mental and physical health of family caregivers. Research has shown that primary family caregivers for a person with Alzheimer's or a related disorder experience a wide range of health effects, from increased depression and anxiety to poor sleep quality or worsening diabetes or heart disease. These negative health effects of long-term stress can happen to family caregivers whether the person with Alzheimer's lives at home or in a care facility.

Primary family caregivers are often too busy or overcommitted to attend classes, workshops or support groups to learn coping skills.

The Williams LifeSkills Program for Reducing Stress and Anger has recently been adapted for at-home use specifically for primary family caregivers of persons with Alzheimer's or a related disorder. This DVD/videotape and workbook, with telephone coaching to adapt skills to individual situations, is being tested for its potential to reduce negative health effects of Alzheimer's caregiver stress. A study will monitor family caregivers as they use the program and coaching to learn stress coping skills that may improve quality of life. Study assessments may be completed at home, and study participants are compensated for their time.

For more information about this study funded by the National Institute on Aging in the Research Triangle area of NC, call Lisa Gwyther, MSW or Edna Ballard, MSW at 800-672-4213 or email Lisa at lpg@geri.duke.edu.

"Duke Family Support Program ... This is Mary"

Can't you just hear the cheerful welcoming voice of Mary Trabert, Program Coordinator of the Duke Family Support Program and Conference Coordinator for the Bryan ADRC? Mary accepted a new position within Duke, an exciting challenge for her. The Duke Aging Center Family Support Program and the Bryan ADRC are indebted to her for her generous spirit, passionate enthusiasm, creativity, consummate professionalism (and gap-filling exceptional organizational skills). We wish her all the best, and we ask your patience during this transition.

Research Roundup

By Rachel Adelson, MA, Live Wire Communications, Raleigh, NC

For brain health, whole foods beat isolated supplements. PET scans don't diagnose Alzheimer's. Dementia drugs don't slow mild cognitive impairment. Brain Bank workers use a lot of ZipLoc® bags. People with Alzheimer's can yuk it up in self-supporting comedy clubs. For end-of-life decisions, families rely more on prior discussions than on formal directives. And to prevent or stall the long slide down into clinical dementia, timing may be everything -- whether for drugs, vitamins or lifestyle change. For one thing, if your blood pressure's creeping up in middle age, get a handle on it *now*.

An Alzheimer's conference gives a lot of take-aways. For my work as a writer/editor in neuroscience and aging, it was helpful to hear the latest research presented at "Alzheimer's 2007: Strategic Directions in Research and Care." The Bryan ADRC clinical team took the audience of more than 450 scientists; health-care, social-service and long-term care providers; and family members, including many research participants, through a thicket of findings on everything from new options for early diagnosis to the risk-laden rise in diabetes.

To demystify diagnosis, the Memory Disorders Clinic team staged a mock clinical evaluation that showed how they work, including psychometric paper-and-pencil testing of key neuropsychological indicators such as working memory and verbal fluency.



Dr. Gary Small introduces memory strategies.

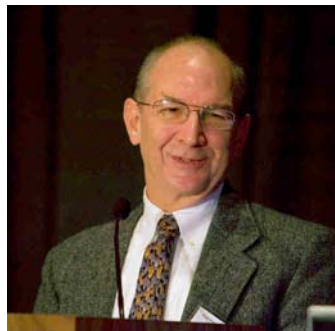


Dr. John Breitner responds to a participant's question.

Drs. Munger, Rabins, Camp & Burke are deluged with questions during the dialogue with participants.

Among the visiting scientists, Gary Small, MD, director of the UCLA Center on Aging, used Hollywood pizzazz to show how memory tricks aid learning ("Does *Harry* look *hairy*?"). John Breitner, MD, of the University of Washington, made sense of conflicting reports on everything from hormone replacement (the jury's still out) to anti-inflammatory drugs (NSAIDS may make things worse). And neuropsychologist Cameron Camp, PhD, of Cleveland's Meyers Research Institute, led two surprisingly uplifting sessions that stressed simple, research-based methods of bringing out the best in people institutionalized with dementia, despite limited budgets and staffing.

And that's just all I had time for. Still, once we were done with the dangers of insulin-resistance (metabolic) syndrome, the mysteries of mild cognitive impairment, and the ethical challenges of late-stage disease, the underlying value was the meeting place itself. People dealing everyday with Alzheimer's learned new methods and insights from the experts. And the experts connected with the people that they ultimately serve, inspired by their questions and compassion.



Dr. Peter Rabins' presentation has a light moment.



Chuck and Linda Hollinshead talk with Dr. James Burke about their research participation & his blog.



The Arts and Alzheimer's: Joel Reibert displays photographs of his grandfather and Elmer Gibson with Lori Barmer plays an original jazz tribute to his parents.



Dr. Kathleen Welsh-Bohmer with Ms. Lena Council, Bryan ADRC GEM research participant.





**Do you suffer from
Alzheimer's Disease
or
have a family
member
who suffers?**

**Duke University Medical Center is conducting
a Research Study Exploring the Effects of an Investigational Drug
on memory function in Alzheimer's patients.**

If you would like more information about this study, please contact:
**Dr. Burke at 919-684-5650 or
Deb Heydt, Study Coordinator,
at 919-668-2843**

IRB # 5743

KnowItAlz.com Blog*

Groundhog Day

Friday, January 19th, 2007

Dad is in a phase now where he repeats everything. He gets his mind on a single subject and asks the same question, or makes the same statement over and over and over.

When is my high school reunion? Where is it? How many classmates will be there? I repeated the answers to these questions about 912 times. "It is next week, it is in Florida, 15 classmates plus spouses."

Here is my solution. I went to my computer and made up a flyer that looked like the class president had mailed it to my dad.

It read "61st High School Class Reunion – January 25th-28th in Naples, FL. Attending are Joe, Bob, Sue, Jane, etc. and posted them around the house.

I have found this method to work in many situations. For a while he was fixated on the weather. "Have you heard a weather forecast?" Now we have daily weather update sheets posted.

It's a little wacky that our house looks like a bulletin board, but oh, well.

* KnowItAlz is a blog (i.e., "Web log") written by Kathy Hatfield of Pfafftown, NC, a caregiver whose father has Alzheimer's Disease. See www.KnowItAlz.com. Reprinted with the author's permission.

Just the Chicken Sandwich

Sunday, January 21st, 2007

My sister, Susan, took Dad to Chick-Fil-A for dinner the other day.

There, in a large frame at the counter, was **the sign**.

It said "We Didn't Invent the Chicken, just the Chicken Sandwich" along with a date - 1946.

Well, unfortunately for the 16-year-old on duty, my father **does** remember a few things (especially from his high school years), and one of them is DISTINCTLY REMEMBERING HAVING A CHICKEN SANDWICH before 1946.

He was horrified at the misleading false representation that THEY had invented the chicken sandwich.

Susan is adding Chick-Fil-A to the list of places not to take Dad for dinner.

I Hope I Never Get Alzheimer's

Sunday, January 22nd, 2007

Dad has no idea he has Alzheimer's disease. He has been told several times by the neurologist, and it has been mentioned a few times by accident in front of him, but he forgets.

Since my sister Nancy and I decided to start KnowItAlz.com, I have been doing a lot of research and getting a lot of info by mail about Alzheimer's, dementia and care giving.

Usually Dad does not pay attention to the mail, but lately he has wanted to check the mailbox to see if there is anything for him. So, he keeps asking me about the Alzheimer's mail and why I am getting it. I did not have an answer prepared, but I am pretty good on my feet. I told him that I am considering a marketing job at the local branch of the Alzheimer's Association. Of course, each time I mention this, he is excited that I may be working for such a great organization. Today, he said, "I hope I never get Alzheimer's."

I replied "me too, Dad, me too."

The bamboo that bends is stronger than the oak that resists.

— Japanese Proverb



Holding on to the “Spirit” of Caring for a Loved One with Dementia

By Nancy Kriseman, MSW
Atlanta, GA

They are often considered “non-persons” because they aren’t able to engage in the world like most of us. Who are they? They are our parents, grandparents, siblings, neighbors, and other loved ones with dementia. In my case, it’s my mother, who was diagnosed with Alzheimer’s disease fifteen years ago. At the time of my mother’s diagnosis, I was working as a geriatric consultant and counselor. Now, I was facing a personal situation that I faced previously only as a professional.



Over many years, I have become painfully aware of how our culture tends to misunderstand the needs of elders with dementia. Too often, professionals talk about Alzheimer’s disease in “doom and gloom” terms. We use language that demoralizes, creates despair and hopelessness and sets up fear. Yet, these very people have contributed to our society for most of their lives.

As a caregiver who is now *intimately* involved in my mother’s life, I have come to realize how important the “*spirit*” is in this journey for both Mom and me. I define “*spirit*” as the part of us that connects solely to our hearts. Our spirit helps express our soul and keeps us connected to one another. For those of us who believe in a higher power, the spirit keeps us connected to one larger than ourselves.

Yet, sadly I have found that both professional and family caregivers assume that once a person loses cognitive and physical capacity, there is really not much left. Even a once popular book on dementia, “Loss of Self,” infers that once a person has moderate dementia he/she loses the essence of self. I began to wonder about the spirit and soul factor in this “loss of self”. Unfortunately, because of this perspective, many professional and family caregivers tend to “give up” on finding ways to tap into the spirit of the person, let alone, consider how to maintain a relationship.

I was determined to have a different perspective and experience with my own mother. I began to explore how my own religious faith—my Judaism, affected me as a caregiver and daughter. I talked with several Rabbis, meditated on how being Jewish could help me to cope and then incorporated more of my Jewish practices and prayers into my everyday life. I would often be surprised by the comfort I felt praying, or saying a particular Jewish prayer or by singing a particular song. Recognizing how helpful this was for me, I decided to expand my exposure to other religious and non-religious practices of spirituality. I became “more conscious” about ways I could invite different spiritual practices into my life. Thus I opened myself to songs, prayers and meditations of different faiths as well.

As another very important part of my spiritual consciousness, I concentrated on bringing experiences and people into my life that helped to *nurture my spirit*. Being both a professional and family caregiver, I became more aware of how I was constantly giving of myself but wasn't making time to *replenish* myself. Bringing consciousness forward, I became committed to choosing to associate with people and experiences that fill my spirit. Thus for me, it meant singing more, listening to music that truly soothed or relaxed or energized me. I danced more for fun, carved out play time with the people in my life who bring me joy and pleasure, and made sure I got my fill of laughter. I reconnected with the creative side of myself that I knew better during my younger years. I now enjoy gardening, photography and other crafts, all of which help me to slow down, and get in touch with my heart.

I also noticed that when I would visit with my mother, and focus more on her spirit, she was better able to connect to me. Thus I began singing with her, listening to music together, sharing foods with her that she loved and that comforted her, and I found that massaging her legs, arms and hands helped soothe her. All this seemed to lift her spirit and mine, helping both of us have more satisfying visits. I will never forget the time when I came to visit her and she was laying in bed, awake. Instead of asking the caregiver to get her up into her wheel chair, I decided to get in bed with her. We giggled, sang songs and just held hands. Both of us had a wonderful time together, just being with one another. What struck me so profoundly was that I never would have considered doing this if Mom hadn't been cognitively impaired. Now it has become a precious, special way I connect with her.

Having such positive experiences with my own mother, encouraged me to begin sharing these experiences with my clients. I began talking with them about the importance of connecting to the spiritual sides of themselves. I have come to realize that much of the depression and sadness that caregivers feel, is from feeling depleted of spirit. While antidepressants and psychotherapy can help one feel better, it doesn't necessarily help to replenish the spirit. Professional and family caregivers alike give so much that their *well* can easily and quickly become dry.

So many caregivers are challenged by lack of resources and supports that previously were available to them. Previously, families lived closer to one another and even houses were closer to each other, thus encouraging a greater sense of community. Businesses provided a more family-like atmosphere. And with added longevity has come chronic illnesses that require more resources to support the emotional, financial, physical and spiritual areas of a person's life.

I now spend a good part of my professional and personal life helping people think differently about this disease so that both the caregivers and their loved ones with dementia don't feel so “DIS-EASED.” Those caring for these elders need help and support so they can nourish and replenish their own *spirits* as they travel down the long and winding road of caregiving.

My experiences with my mother, combined with my clients' feedback inspired me to develop a caregiver support program, called “**The Caring Spirit.**” I captured my techniques in a book entitled, “The Caring Spirit Approach to Eldercare.” I have come to value the “importance and power of the spirit” in the caregiving relationship.

I share my experiences so others can hold on to hope and have faith that both the *spirits* of the elders with dementia and the caregiver's *spirits* can remain intact. There are gifts and blessings to behold.

Kriseman, N. (2005) The Caring Spirit Approach to Eldercare. Baltimore, MD: Health Professions Press.

Happiness is a butterfly, which when pursued is just beyond your grasp, but which, if you sit down quietly, may alight upon you. Nathaniel Hawthorne

The Top Ten Things Caregivers Don't Want to Hear.... And a Few Things They Do

By Carol Levine, Director of the Families and Health Care Project, United Hospital Fund, New York, NY

I've been a family caregiver for my disabled husband for nearly 17 years, and in that time I've been given all kinds of unsolicited advice, unwelcome criticism, and undeserved praise. I've developed a thick skin and some stock replies. But, I wondered, am I alone in feeling frustrated at the insensitivity of some of these comments, particularly when they come from casual acquaintances or marginally involved professionals? Apparently not! I sent a query to a caregiving listserv and other caregiving venues, and was deluged with responses.

I've edited, collapsed, and compiled the results, many of which match my own favorites but some of which relate to other situations. Not every response could be included and every caregiver will probably have a different list or a different ranking. Here then are my candidates (with a nod to David Letterman):

No. 10 – Doesn't Medicare (or your insurance) pay for that?

People who have no experience with long-term chronic care are unaware that Medicare and private insurance do not cover most of what is needed to keep a family member at home or in assisted living or nursing homes beyond short stays after hospitalization. Only Medicaid, which requires impoverishment, pays for long-term care, and even that program varies by state and is still biased toward institutional care. Enlightening the uninformed is tedious but perhaps serves an educational purpose. If these folks understood the financial burden and unending responsibilities of long-term care, then maybe they wouldn't say things like "Where are you going on your vacation?" or...

No. 9 – It must be hard to work and take care of your husband, so why don't you just quit your job?

My guess is that this is a question asked only of women, since men are presumed to have a greater personal and financial attachment to their jobs. Beyond the financial necessity, especially for women who are heads of households, work for many caregivers is an affirmation of their worth beyond caregiving, a source of friendship and stimulation, and a welcome balance to their lives. Others do leave the workforce, but at considerable cost to their current financial status and future retirement or employment opportunities. It's not a decision to be taken impulsively. A good friend or concerned family member can certainly help a caregiver weigh the options objectively.

No. 8 – Your mother belongs in a nursing home.

OR: I could never put my mother in a nursing home.

This is one of those statements that offends either way it is offered. The first formulation suggests that the caregiver is not capable of providing good care, or that Mother is dispensable. The second is a clear criticism of the caregiver who, after considerable anguish, decides that the only solution is indeed a nursing home. Well-wishers should avoid making quick judgments, which mainly serve to make the caregiver feel guilty. There is a place, of course, for candid discussion about whether the caregiver can continue to provide care at home. (Big exception: If Mother is truly being neglected or abused, then a professional intervention is in order.)

No. 7 – You have to take care of yourself; your husband (mother, father) needs you!

Of course, caregivers should take care of themselves; but why does it have to be linked to another person's need? Am I not worthy of good health for myself? And how exactly am I to find time to rest, exercise, prepare balanced meals, see the doctor, and do all the other things I should do? And if I don't do them and my health suffers, is it my own fault? Unfortunately, many caregivers do see themselves only as extensions of the person they are caring for, and still they don't take good care of themselves. And if a caregiver starts to explain why she doesn't follow all the good health rules, she is likely to be asked.....

No. 6 – Why don't you get your family to help out more?

This deceptively simple question steps on a huge emotional landmine. Some families cooperate without any hesitation or difficulty; in others, sharing responsibility is fraught with emotional traps. Some caregivers choose, for their own reasons, not to rely on other family members; others would like the help but either don't get it or find it comes with too many conditions. A trained professional can mediate and perhaps work out an acceptable division of labor. When some family members are not closely involved in care, they may say things like

No. 5 – I don't see what you're complaining about. Dad seems fine to me.

Elderly Dads and Moms have an uncanny ability to marshal their resources for the occasional visit of the out-of-town or uninvolved child, making the caregiving child's accounts of their behavior seem unreasonable. This statement has many variations: "Dad always got lost and drove too fast"; "Mom never could balance a checkbook"; "I forget things too." Less-involved siblings should make it a point to drop in unannounced and stay for a long enough time to see how Mom or Dad act under everyday circumstances.

No. 4 – I don't know how you do it. You must be a saint.

For a caregiver beset with frustration, depression, anxiety, and exhaustion, being told that you're a saint is decidedly unhelpful. (There may be some exceptions among those who aspire to martyrdom.) While this statement is surely meant to express admiration, it has the unintended or perhaps unconsciously intended result of distancing the speaker from the caregiver. After all, how many saints are there in the world? And if the caregiver is one, then the noncaregiver certainly won't be called upon to be one. Instead of sanctification, most caregivers would prefer a little help, which leads me to....

No. 3 – Just call me if you need some help.

This is sometimes phrased as "I wish there were something I could do to help." Most caregivers have learned that imprecise, indefinite, offhand offers of help are expressions of good will but little else. The speaker feels better ---"After all, I did offer, and she never called," while the caregiver thinks, "What exactly does she mean by 'help'?" Friends or other family members who really want to help should make specific offers such as, "I'm going to the farmer's market; can I bring you some vegetables?" "I can stay with Mom on Saturday so you can do some shopping or go to a movie." "I know it's hard for you to get out for dinner, so I'd like to bring dinner to you one night this week." These are small things; the list could get progressively more complex and demanding. But whatever the offer, it should be firm and nonrefundable.

No. 2 – I know just how you feel.

This is another attempt at solidarity that fails. The caregiver is probably thinking, "No, you don't because sometimes I don't even know myself how I feel." Caregiving involves a complex and dynamic array of emotions, which each person experiences and internalizes differently. This

statement shifts the focus away from the caregiver to the speaker, who frequently follows it up by talking about his or her own caregiving experience.

No. 1 – God doesn't give you more than you can handle.

No. 1 on my list showed up surprisingly frequently on other people's lists, including members of the clergy, as well. This statement, sometimes phrased as "Don't worry, God will be good" is intended to be comforting, and for many people it may be. They need read no further. Why then do so many people find it upsetting? For me, the primary reason is that it is demonstrably untrue. Millions of individuals succumb to what God, fate, natural disaster, violence, or political, social, or economic turmoil have wrought. For caregiving specifically, studies have demonstrated that spousal caregivers are at increased risk of dying compared to their noncaregiving peers. And even if they don't die, their health and well-being are permanently affected. Unlike patient, long-suffering Job in the Bible, caregivers' losses are not repaid twice over when the challenge match between God and Satan is concluded. (What would I do with 6,000 camels anyway?) As Rabbi Gerald Wolpe, himself a caregiver, points out, Mrs. Job, the caregiver, is disdained and disregarded, and the new children given to Job do not replace those she has lost. From the Christian tradition, Kenneth Doka, a Lutheran minister and gerontologist, says, "Only the caregiver knows the extent to which he or she can bear a particular burden, and such comments could make the caregiver feel inadequate and unworthy." Rev. Andy Calder, an Australian minister, says: "People hear these statements as clichés of judgment – of God being against them. The recipients are cast as people whose faith is perhaps suspect, as people who have perhaps incurred God's wrath for some misdeed, and as people who have no control over their circumstances: indeed, as victims." For me, the most helpful approach comes from Rabbi Harold Kushner, author of *When Bad Things Happen to Good People*, who says: "[Bad things] do not happen for any good reason which would cause us to accept them willingly. But we can give them a meaning." Prayer, spiritual solace, and religious rituals can help give meaning to caregiving, as can many other responses. Easy answers do not suffice.

So that's my "how not to" list.

And here are a few additional suggestions for the "how to" list.

No. 3 – I have a friend who is having a lot of difficulty getting started as a caregiver. Would you be willing to talk to her?

Generally caregivers are very willing to help each other, as long as there are clear boundaries. Giving back what one has learned from painful experience can be gratifying. The decision, of course, depends on timing and mutuality of experiences.

No. 2 – I haven't seen you in a while, and I miss our (lunches, shopping, bowling, volunteering, whatever). Caregivers are isolated. Phone calls can be welcome invitations to rejoin the world. Ideally, of course, the caller will follow up with a specific plan to meet.

No. 1 – How are you doing? Some people ignore the caregiver altogether, looking the other way so that they do not have to have any conversation at all. Many people will ask about the ill person but not the caregiver. It's appropriate for family and friends to ask about the care recipient but they should be sure to follow it up with concern about the caregiver. And then they should follow the caregiver's lead. Sometimes he or she will want to talk about caregiving, and sometimes about something—anything—completely different. Listening well is the best support one can give, and the best support a caregiver can receive.

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Editor's note: Ms. Levine's husband died December 31, 2006.

I've Lost Me

By Virginia Carswell Parrish
Valdese, North Carolina
January 23, 2007

I've lost my joy,
Will to live,
Desire to care,
Ability to love.
I've lost me.

Where did I go?
My husband left me...
Not because he wanted to.
His earthly days were through.
Thirty years of my life left with him.

Where do I go now?
No matter where I go,
Who I talk to,
What I do, I'm alone.
Caught in a capsule of time
Where I've been.

Where I've been doesn't matter.
What matters is where I'm going...
And how I get there.
Where do I want to go?
What must I do to get there?

Youth has fled.
Beauty has faded.
Pain cannot be denied.
Dreams have been dreamed.
The future holds no promise.

Acceptance must come first.
Life needs to be lived or lost.
Surviving and moving on comes with a price...
Leaving behind what was, to search for what will be.
Am I willing to invest the time, my heart, me?

I want to live again, care about others, and love.
It will take awhile to find the new me.
I will step out in faith, trust God, and pray.
I will find out where I'm going and
Decide what I need to do to get there.



***Courage does not always roar.
Sometimes, it is a quiet voice
At the end of the day saying,
"I will try again tomorrow."***

Anonymous

The Real Story: A Daughter's Journal

By Nancy Nagy,
Winston-Salem, NC

I hear someone say, "He must be going through his second childhood." Everyone laughs, and I think that it will never happen to me. Then I find out that my mother has Alzheimer's disease. I tell everyone that I am going to take care of her. They applaud my fortitude and tell me how great I am. This is when reality sets in. I read article after article on the disease. I read articles about how Alzheimer's has robbed people of a loved one. I read support group notes on how to cope. I read The 36 Hour Day. But I haven't read any articles about what it is really like to be a caregiver for a mother with Alzheimer's.

My mother was diagnosed with Alzheimer's nine years ago. I have been caring for my mother for eight years. I quit my job five years ago to stay home with her full-time. This is what my life is like now.



I have a baby monitor beside my bed again, and my day begins when I hear, "I want to get up." Or I hear the rattle of bed sheets as she tries to get out of bed. It reminds me of when my children were small. I would be asleep and the next thing I knew, I would have sticky fingers poking me in the eye, telling me it is time to get up.

Before I even get a cup of coffee, I am giving her a bath and dressing her. I take her to the table for breakfast, put a bib on her to keep her clothes clean and feed her breakfast. If it is a good day, she eats with little fuss. If not, she winds up with breakfast all over her and the floor. It reminds me of when my children were small and they would rather play with their food than eat it.

My house is devoid of all the little knick knacks collected over the years. The doors to the outside have locks on them to keep Mom inside. She has a bracelet with her name and address on it in case she wanders off. I have put the matches away, locked all the cabinets where chemicals are stored, and made sure there are no obstacles in her path to trip over. In other words, my home is "Mom-proofed".

If I want to go someplace, I have to line up a sitter, or make arrangements for a day center. Mom seems to sense a break in routine and becomes "cranky". If I take her to a day center, "I don't want to stay", "When are you coming back?", or "I don't like it here," are some of the remarks I hear as I take her in the door. Sound familiar? I remember the traumatic experience of dropping my child off at day care so I could work.

I remember the sleepless night of a crying baby. At that time, my children were too young to tell me what hurt, or what they wanted. Now, Mom is just not sleepy, or she wants to go home, or plain and simply, she does not want to go to bed. Getting her nights and days mixed up is common. I try to keep her up during the day so she'll sleep at night. I remember how I would lie down with my children until they fell asleep. Now, I sleep on the floor of her room to keep her quiet so everyone else can sleep. I no longer get six to eight hours of sleep; I get snatches of two or

three hours at a time. It is like the two o'clock feedings all over again. Only, with my children, I knew that eventually, they would sleep all night. Now I realize that it can only get worse.

I remember the feeling of accomplishment when I finally potty-trained my children. Now I have to start all over again, only in reverse. At first, it was only every now and then. As time went on, I started using disposable underwear, hoping to save time and clothes. Now, it has progressed to every time she goes to the bathroom. I am changing underwear and clothes two or three times a day. I am buying ointments and baby powder to try to stay ahead of the sore bottom and rashes. Applying the ointment brings tears because it burns. Instead of washing clothes once a week, I am washing every other day to keep clean clothes available. The bed sheets are washed everyday. I have rubber sheets to protect the mattress and egg-crate pads to help keep bed sores at bay.

The first time my child smiled at me and I knew he recognized me was the happiest day of my life. I told everyone I knew. With Mom, I do the same thing. However, instead of rejoicing in the knowledge of the smile, I am praying that the recognition will last. I pray that this time, she will always remember me. Yet I know that in time all recognition will fade away and she will no longer know me or anyone in the family.

Going out to dinner with my children was always quite an adventure. I never knew if they would behave or throw a tantrum. Nothing has really changed. I'm still placing the order, cutting the meat and hoping she gets more in her mouth than on her clothes. I never know if she will use a fork, a spoon, or her hands. Being in a crowd causes her to become anxious. Strangers don't exactly upset her as much as excite her. Getting her to calm down afterward takes time. Or, it tires her and she becomes cranky. If however I am lucky, she gets tired and falls asleep. I gave up going out to dinner because of the effect it has on her. I don't entertain anymore because it has the same effect on her. Family gatherings have become a balancing act between hostess and taking care of her.

By the end of the day, I am exhausted. I only want to fall into bed and get eight hours of uninterrupted sleep. I pray that tonight she will sleep, and I won't have to get up with her for her "two o'clock feeding."

There is one effect of my becoming a caregiver. Family and friends basically abandoned me. The reasons:

- I can no longer join in the outside activities they have planned because everything is contingent on getting a sitter or getting Mom to a day center.
- I quit extending invitations to friends and family because I don't want to upset her..
- Family quits visiting because she doesn't recognize them or remember their names. Why visit if she doesn't remember they were there?
- I don't want the embarrassment of having to change her diapers in front of guests or having guests watch her play with her food.
- I don't want to intrude on their busy lives.

When I announced I was going to take care of my mother, everyone promised to help. But, they feel helpless around Mom. They haven't spent enough time with Mom to know her little idiosyncrasies. It is a catch-22 situation.

I think caregivers should be prepared to go it alone with a little help from strangers. Reading an article on how someone felt when their parent succumbed to Alzheimer's doesn't really help me. I know how they felt. I am dealing with it every day. Reading an article on "how to cope" makes me feel inadequate. Telling me not to get angry or not to raise my voice only makes me feel like I am doing an awful job taking care of my mother. The truth is, I do get angry, and I do raise my voice. I am angry because this disease has taken the person I knew and turned her in to someone else. I feel like I am taking care of a child again, but this child weighs over 150 pounds and was once my Mother.



“When Dad Refuses to Give Up the Car Keys”: What Are Your Options?

By Florence Ikechukwu, Social Work Intern

Independence and mobility are critical to maintaining quality of life for most individuals; therefore, ensuring that the person with Alzheimer's disease retains his driving privileges for as long as it is safe to drive is vital. However, when driving safety is in question, the concerns should be addressed in a careful, sensitive and respectful manner. There is no formula that works 100 percent of the time.

Driving involves quick coordination of complex activities requiring precision, alertness, split-second decision-making and responses to multiple stimuli. Individuals with Alzheimer's experience losses in reasoning, visual response times, and judgment. Additionally, there are problems with disorientation, attention span and decreasing ability to recognize cues such as exit and directional signs. These multilayered impairments diminish the individual's capacity and eventually pose a danger to himself or others on the road.

Signs that driving is no longer safe: The decision to stop driving must not be based on diagnosis or a single episode of poor driving, but rather on the outcome of careful monitoring and evaluation of the person's driving ability. Some people with early Alzheimer's continue driving, but they drive only on familiar roads, during daytime hours and they avoid bad weather and heavy traffic.

Signs of serious driving problems include: confusion at exits, incorrect signaling, running a red light or stop sign, stopping at a junction or in the middle of the road, trouble navigating turns; moving in the wrong lane; driving at inappropriate speeds; delayed responses to unexpected situations; scrapes or dents on car, garage or mailbox; getting lost in familiar places; driving with no memory of where he or she is going; giving up on locating the car in a parking lot; traffic violations or warnings; fender-benders; confusing the brake and gas pedals; getting agitated when driving and making excuses for minor accidents.

Respectful ways to persuade a family member with Alzheimer's to stop driving: Involving the individual with Alzheimer's, the caregivers and other relevant professionals such as the physician in decisions about his or her driving is a crucial step in respecting the individual's dignity, sense of worth and ability to “save face”. Here are helpful steps in addressing the problem:

Step 1: Information Gathering: Pay close attention to the individual's driving behaviors over time as well as driving concerns of other family members, friends, and neighbors. Arrange a calm setting and time to talk with the person about his feelings, concerns and challenges when driving. Remember this is a sensitive issue and the person may become defensive. It's best not to gang up as a group on the person.

Step 2: Sharing Driving Concerns and Safety Implications: Everyone involved should have a defined goal, either to limit driving or for the person to “retire” from driving; and the goal should be consistently reinforced by everyone involved. If possible, ask a friend or neighbor who is no longer driving how he or she manages. Discuss benefits of not driving such as saving money on insurance payments, car repair or paying for gas. Discuss other ways to meet mobility needs such as having a friend or relative drive.

Step 3: Explore Driving Needs and Develop a Plan to Meet the Needs: Write down each identified driving need. Engage the individual with the support of family and friends. Could a neighbor or family member help with grocery shopping, or drive him to appointments or regular club activities? At times waiting for a ride or having to ask or plan ahead for a ride can be very hard. Families can be creative. For instance, a beloved grandchild who needs a car to go to school could provide a ride in exchange for the car. Identify alternative services in the community that could be harnessed to meet needs such as disability access transportation, or home delivery services. Prepare a sign-up sheet for each family member or friend to identify the role he/she could play to ease the loss of driving. Boldly write the contact and telephone numbers of each of these volunteers and place them in a conspicuous place.

Step 4: The Last Resort: There are situations when the individual might insist on driving despite efforts to meet his driving needs, his safety and that of others. In such a situation, it is absolutely imperative to apply more stringent measures to ensure safety. In fairness, it is critical that the basic and social driving needs of the individual are consistently met before applying these measures to reduce frustrations and anger. Some of such measures include the following: Ask your doctor to tell the impaired person it’s time to “retire” from driving, or write a prescription saying “No driving while on this new medication.” Write your local Department of Motor Vehicles (DMV) about the doctor’s recommendation and the family’s concerns. Follow up and ensure that DMV re-evaluates the individual. The doctor may request a driving evaluation from an occupational therapist. You may wish to replace his car key with a similar key that won’t start his vehicle or park the car out of sight and explain that it is being repaired. It might be necessary to arrange with a mechanic to install a “kill wire” that can prevent the car from starting or to disable the car or consider selling the car.

Alzheimer’s disease eventually affects driving ability; therefore, the driving skill of a family member with Alzheimer’s should be monitored closely. When driving poses safety risks, tactful and concerted efforts must be applied to stop driving. Family members should remain sensitive to important social needs of the individual with Alzheimer’s disease.

Editor’s Note:

AARP NC offers “We Need to Talk ... Family Conversations with Older Drivers,” free 60-90 minute seminars presented by volunteer facilitators. If you are interested in facilitating or attending this program, contact Suzanne LaFollette-Black, Associate State Director, AARP NC, 1-866-389-5650, 1-919-508-0269 or via email at slcameron@aarp.org. Additional information is available online at www.aarp.org/drivers, www.thehartford.com/alzheimers, and http://web.mit.edu/agelab/projects_driving.shtml.



What Not to Ask a Caregiver

By Carol Kelly
Chapel Hill, NC

“Does your father know who you are?”

I cared for my dad for many years, and now I care for my aunt, his sister, who has dementia. The first thing people ask typically is “Does he know who you are?” How heartbreaking to think he would not know me! Sometimes my dad might not have been able to put it in words, but I know he always recognized my presence. He knew I was family and someone who cared. Who would want to admit a loved one didn’t know them? If they do admit it, let them tell you, DON’T ASK.

Everyday I visited my dad or saw my aunt, staff members or visitors would ask him or her: “Do you remember me?” Or staff members would often say to my father, “Do you know who this is?” looking at me. It was demeaning and unnecessary. Why quiz him and add to his stress? Can each one of us always remember names of people we have met? Why not just make it easier and say, “Hi Mr. Jones, it’s Susan and I wanted to say hello.” I did all I could to make things easy on Dad, like labeling photographs with names so he would not have to struggle to remember.

“It must be nice to be retired.”

I took early retirement. I was fortunate to be able to afford to devote time to my father and his sister. I even bought an apartment near their care facility because my home is out-of-state. Their needs have varied the past few years. Once my aunt broke her hip and fractured her neck. I was with her nearly every moment through surgery and rehab. Many days I would be with her and my dad from early morning until they went to bed, seven days a week. Then I’d run into a friend who would say, “Gee, it must be nice to be retired.” I was putting in more time than when I worked, and I had left a very demanding job as a school principal. People just don’t have a clue what it takes to care for someone, maintain contact with paid caregivers, do banking and run other necessary errands. To make matters worse, some people question why I visit so often, “Gee, they are in a nice facility and being taken care of, so why do you visit?”

“So what should we ask?”

You can help support family caregivers. Ask how they are doing. Ask about their personal health. Are they putting themselves at risk by neglecting personal needs? Ask what you can do to help. Help them get out for a walk or to dinner. Send a note. Just checking in with a phone call now and then may do wonders. Let family caregivers talk about themselves and their plans for the future. Let them know you are there for them, and that they are not alone.

Doing your best at this moment puts you in the best place for the next moment.

Oprah Winfrey

New Web Content



http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1454 Be Wise ... Immunize! A Fact Sheet for Caregivers from the Family Caregiver Alliance.

http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1742 Updated Residential Care Options Fact Sheet from the Family Caregiver Alliance.

<http://seriousillness.org/demo/programs/index.php?catego=57> Lists online support groups for Alzheimer's, bereavement, caregiving, cancer and diabetes.

www.adultmeducation.com/consumerinformation.html Includes medication questions for consumers and their pharmacists to improve safe and effective medication use.

www.ahrq.gov/QuestionsAreTheAnswer/ Features a "Question Builder" prompting patients to select from a list of targeted questions and print out a customized list to bring to health care appointments.

www.alz.org/messageboards Online message boards and chat rooms available 24/7 for support for people with Alzheimer's, family caregivers, professionals. Browse anonymously, no sign-up required and no personal data captured.

www.alz.washington.edu/NONMEMBER/nlttr.html Newsletters published by NIA Alzheimer's Disease Centers.

www.alzheimerbc.org/newsletter.php Index of articles from Alzheimer Society, British Columbia titled "Insight – For and By People with Dementia"

www.alzheimers.org.uk/I_have_dementia/newsletter/index.htm Alzheimer Society of UK newsletter – pdf file for people living with dementia.

www.alzscot.org/pages/info/helpcard.htm Alzheimer Scotland information about a "helpcard" to increase public understanding about how a person with dementia might need help in different situations.

www.benefitscheckup.org National Council on Aging's BenefitsCheckUp now allows automatic filing for Medicare Extra Help and other needed benefits.

www.caregiving.org/medicare/index.htm New advice sections added to Medicare Interactive from the National Alliance for Caregiving.

www.cdc.gov/nip/vaccine/zoster/default.htm National Immunization Program: information page for shingles (herpes zoster) vaccine.

www.consumerreports.org/cro/health-fitness/nursing-home-guide/0608_nursing-home-guide.htm September 2006 - US Nursing Homes Rated. Site makes a strong case for starting a nursing home search with not-for-profit establishments.

www.elderlawanswers.com/resources/article.asp?id=5259§ion=4&state= The Ethical Will: Making Room for Your Voice.

www.epa.gov/aging New information on protecting the environmental health of older persons.

www.epa.gov/aging/resources/factsheets/ww_english_2006_01.pdf Safe water fact sheet for older adults and family caregivers.

www.longtermcare.gov US Department of Health and Human Services' new site about long-term services and financing with tools to begin the planning process.

www.nia.nih.gov/Alzheimers/Resources/SearchHealthLiterature Online interface for searching NIA's extensive collection of health literature on Alzheimer's disease.

www.netofcare.org Homepage and Newsletter of the Family Caregiver Program of Beth Israel Medical Center's Department of Pain Medicine and Palliative Care.

www.pparx.org Partnership for Prescription Assistance offers a single point of access to more than 475 public and private programs assisting patients in paying for their medications.

www.thestatus.com Provides a free, secure, private web communication tool for patients, families and friends. Patients can create their own personal pages in English, Spanish, or French, which may be password protected or left open for public view.

Tips for Resolving Medicare and Private Insurance Issues

Before you pick up the phone to call the insurance company, either on your own behalf or on behalf of a loved one, make sure you have carefully **read all the documents** you want to discuss. Make a **list of questions** you plan to ask or items you want addressed so you'll remember all of them.

When you are ready to call, have all of the documents and your list of questions in front of you for ready reference. And be ready to share the following information:

- The insured person's **birth date**;
- The insured person's insurance **policy number** and **Social Security number**;
- The **name and address** of the organization that sent the bill;
- The **total amount** of the bill;
- The **diagnosis code** on the bill;
- The **Medicare Summary Notice** from Medicare or the **Explanation of Benefits** from your Medicare private health plan (if you are questioning an insurance payment).

Once you are on the phone

- Always write down the **name and telephone extension** of the person handling your phone call. If someone is unwilling or unable to help you or tell you their name, ask to speak to the supervisor.
- **Take good notes**, jotting down the date of the call and the information you were given, including what you were told would be done or what you are to do next.
- **Be patient**, because you will probably spend some time navigating automated telephone menus and waiting on hold.

If the insurance representative asks you to submit additional information, send it right away and keep a copy of anything you send.

Source: Marci's Medicare Update Vol. 6, Issue 12, Mar. 19, 2007



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